



Pennsylvania Polio Survivors

Information and Inspiration for Polio Survivors and
Their Families

From the Keystone State and Beyond

www.papolionetwork.org

January 2017

Our Mission:

*To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups,
Survivor's Families and their Caregivers.*

Winter is here and for so many of us it's COLD outside. We hope connecting with each other makes us all feel a little warmer. This month we have some interesting "It's a new year, let's look at things anew" ideas to share.

**Post-Polio Health International posted a really interesting article –
"Chronic Illness Masquerading as Acute Problem: Post-Polio Syndrome"**

When we shared it with our Pennsylvania Polio Survivor's Network Facebook Group, there was some outstanding discussion and a question that we forwarded on to Dr. DeMayo.

We have given you the original article along with Dr. William DeMayo's response to the question.

**Dr. Bruno must have had similar New Year's renewal in mind,
when he posted this article in the Post-Polio Coffee House**

"A Baby Boomer's New Year Resolution: Ask Your Doctor About Your Medicines"

This is only one of many issues that were covered in December's issue of "Bruno Bytes"

There are always so many questions from Polio Survivors about Bracing.

As a result we are sharing a "Polio Place" interview with Dr. Marny K. Eulberg, MD.

Dr. Eulberg is a polio survivor and family practice physician from Colorado.
(Polio Place can be found on PHI's website: www.post-polio.org)

We are especially grateful for your input and support.

Thank you Ann Silcox for your touch of "humor" for us this month.

Philip Minter shared two wonderful DVD's with us – both from our friends in Australia.

"The Polio Crusade" (a documentary) and "PPS – The Australian Experience"

Can be accessed from our "What's New" page: [HERE](#)



Are you going to Florida this winter?

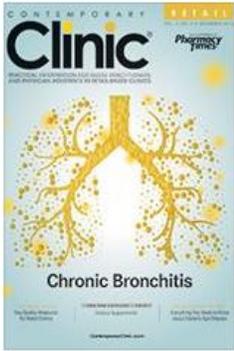
**There are PPS Support Groups located all over
the Sunshine State. They would love to have you visit.**

Check out our "Snowbird" Connection [HERE](#)

Not online? As always, feel free to contact us.



Contact us: papolionetwork@gmail.com (or) 215-858-4643
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Chronic Illness Masquerading as Acute Problem: Post-Polio Syndrome

Jeannette Y. Wick, RPh, MBA, FASCP
Published Online: Friday, December 30th, 2016

At a community event, a 72-year-old woman complained to her companions about pain that had developed in her leg, and various clinicians' inability to help her find relief. The conversation eventually turned toward memories from early life. The woman told a story about running in grammar school, indicating she was the fastest among both girls and boys until she developed polio. A clinician who was coincidentally engaged in the conversation made an important link—this woman's polio could be the cause of her pain. He asked if she had mentioned the polio to her physicians. She had not.

Viral polio infections peaked in the 1940s and 1950s, infecting approximately 500,000 people annually around the world. Many people suffered mild symptoms such as headache and malaise, but some developed paralysis quickly. Children were less likely than adults to be paralyzed; 1 in 1000 children experienced paralysis compared with 1 in 75 adults. During the nation's worst outbreak (the 1952 epidemic), the CDC tracked 57,628 cases and 3145 people died. More than 21,000 Americans developed mild to disabling paralysis that year.

The nation has been quick to forget polio and its disabling effects—after all, we have had an effective vaccine since 1955. However, people who were infected with polio as children are now in their 60s and 70s, and researchers have identified a lingering effect of poliovirus infection: post-polio syndrome.

Post-polio syndrome affects polio survivors 30 to 40 years after they've recovered from their initial poliomyelitis. The cause of the syndrome is unknown but seems to be related to degenerating nerve cells. It tends to progress slowly, waxes and wanes, and is potentially disabling. Up to half of people who had polio at a young age may experience post-polio syndrome. People who are at increased risk are those who recovered from more severe polio, with greater loss of muscle function and more severe fatigue. Those who contracted polio as an adolescent or adult are more likely to develop post-polio syndrome. In addition, people who are physically active are at elevated risk.

Common signs and symptoms of post-polio syndrome include the following:

Progressive muscle and joint weakness and pain

- Fatigue and exhaustion with minimal exertion
- Muscle atrophy
- Breathing or swallowing problems
- Sleep-related breathing disorders, such as sleep apnea
- Decreased ability to tolerate cold temperatures

Diagnosis is based on the presence of 5 factors: prior paralytic poliomyelitis with evidence of motor neuron loss; a period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval of at least 15 years of stable neuromuscular function; slowly progressive, persistent new muscle weakness or decreased endurance, with or without generalized fatigue, muscle atrophy, or muscle and joint pain; symptoms lasting at least a year; and the exclusion of other neuromuscular, medical, and skeletal abnormalities as causes.

Suspect post-polio syndrome when patients meet these diagnostic criteria. Patients may need muscle-strengthening physical or occupational therapy*. Advising patients to rest when necessary is important. In addition to prescribing nonsteroidal anti-inflammatory drugs, a trial with lamotrigine may be helpful.

* **Editor's note:** Only as supervised by a PPS knowledgeable PT/OT &/or/ Rehabilitation Physician

<http://contemporaryclinic.pharmacytimes.com/chronic-care/chronic-illness-masquerading-as-acute-problem-post-polio-syndrome>

When we shared the article (previous page) on our Pa. Polio Survivors Facebook page, an outstanding question came up. Dr. DeMayo was happy to address the question at hand:

Medications and PPS

A Question for Dr. William DeMayo, MD

[DeMayo's Q & A Clinic](#)

Question: "Lamotrigine is used alone or with other medications to prevent and control seizures. It may also be used to help prevent the extreme mood swings of bipolar disorder in adults." The preceding statement is from WebMD regarding the use of Lamotrigine. Why would an article published by a reputable resource refer to such a drug to help with PPS?

Answer: As with many questions discussed in this column, there can be a "short" answer or more extensive discussion using this issue as a platform for thinking about medications in general. First, the "short" answer.... **There is no clear answer.**

What is clear is that there is no "magic bullet" medication that helps all patients with PPS. Lamotrigine has been studied, but evidence is weak. To be fair, the article referred to above simply states "In addition to prescribing nonsteroidal anti-inflammatory drugs, a trial of Lamotrigine may be helpful" The main research that is usually quoted involves only 30 patients with half (15) receiving medication. Although "significant" benefit was documented, there were many flaws in the study, including;

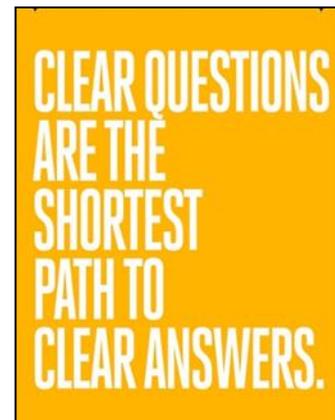


- Very small size of study group.
- "Control" group did not receive a placebo.
 - When testing medication is important to realize that simply the act of taking medication, even a sugar pill placebo, can generate significant benefits and side effects. It is important that both groups receive either the "test medication" or "placebo" so that any benefit from placebo can be subtracted from the measured benefit of the test medication.
- The duration of the study was quite brief.
- Many other interventions were made during the study. These included education, exercise, orthotics, and weight loss.

Some of these criticisms are outlined in the last section of the paper itself (from the Journal Neurorehabilitation) which can be viewed [HERE](#). Although the numbers were small and study design was flawed, there was a possible benefit noted. Also, there is some theoretical reason to consider this medication given its effect on [presynaptic neurons](#) and mood.

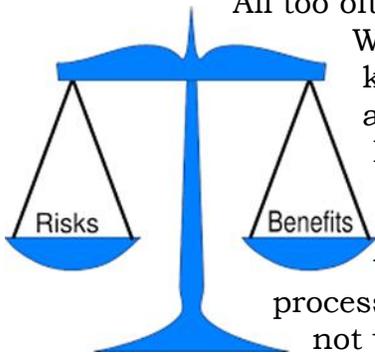
This leads to a more general discussion about the role of medications and when a trial of medications is appropriate. In my opinion, several things should be considered before a trial of medications including:

- What is the specific goal?-"Feeling better" is not a specific goal.
- How will the goal be measured?
 - Numeric pain scale.
 - Functional goal.
 - Other
- What is the specific threshold of improvement that will be used to justify continuation of medication? Examples might include:
 - Reduction of pain from 7/10 to 3/10.
 - Improving endurance to allow individual to prepare a meal without taking a break.
 - Increase ambulation from 1,200 steps per day to 2,000 steps per day on a Fitbit or other activity monitor. (If it is appropriate for the patient to do so).
- What are the specific risks of the medication?
 - Long-term/serious risk to health.
 - Short-term side effects.



(continued . . .)

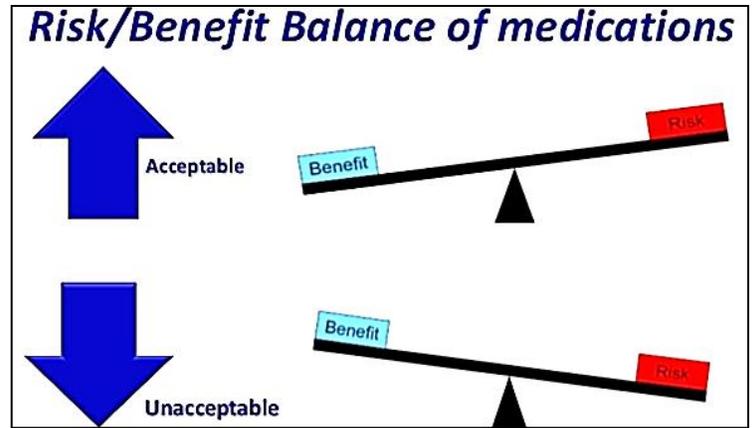
- If any are occurring-should medication be reduced in dose or discontinued by patient?
 - Are there non medication ways to achieve the same goals?
 - o Exercise.
 - o Activity modification
 - o Other?



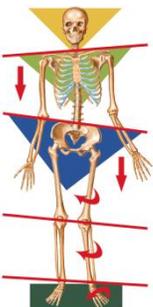
All too often medications are initiated with little or no consideration to the above. When this occurs individuals often end up on multiple medications (also known as “polypharmacy”), resulting in interactions between medications and potential for overall decline in function rather than improvement. Many individuals see this occur in friends and family and take an approach of reject any suggested medication rather than the more rational approach of carefully considering the above questions, and then weighing risks and benefits. This evaluation should be an ongoing process to be sure that medications are providing clear long-term benefit. It is not uncommon for certain problems such as neuropathic pain to “burnout”

and medications that were initially beneficial are no longer needed. If dosages are never reduced on a trial basis then one cannot be sure that there is ongoing acceptable benefit. This should be coordinated closely with the prescribing physician with clear parameters for dose adjustments and changes in outcome that would trigger further dose change or discontinuation of medication.

Outside the polio population, there is an epidemic in our society that views narcotics as the answer to pain without looking at the enormous risks involved. I am equally amazed at the number of people that say they do not “believe in medications”. In my opinion these individuals are focused on risk and not weighing appropriate benefit. They often are operating from a perspective of fear. The same individual might get diagnosed with severe diabetes, and suddenly “believe” in insulin or be diagnosed with a very curable leukemia and “believe” in taking poison (also known as chemotherapy) in order to save their life. The fact is that most medication decisions are not black-and-white and involve the difficult process of engaging facts on an ongoing basis rather than making more simplistic decisions based on limited information or emotion.



Getting back to our original question regarding Lamotrigine, I applaud the author of the question who dares to ask the question “why?”. While in this case the answers are not clear, decisions can be made with a knowledgeable physician, a trial considered, and continuation of the medication can be based on measurable response for the individual. Unfortunately, large randomized controlled trials in the PPS population are not likely to occur and so individualized plans with close monitoring by your physician, as described above, is a rational approach.



Do you have a question for Dr. DeMayo?

Feel free to contact us: papolionetwork@gmail.com

You can read Dr. William DeMayo’s entire series of articles on our website:

<http://www.papolionetwork.org/demayos-q--a-clinic.html>

What IS a Psychiatrist? There are 4 articles relating to this on our website:

<http://www.papolionetwork.org/pps-health-care-providers.html>



“Bruno Bytes”

From Dr. Richard L. Bruno, PhD
and the Post-Polio Coffee House

<http://www.papolionetwork.org/bruno-bytes.html>

On the topic of asking our Physicians about Medications (12/26/2016)

Dr. Bruno’s Original Post: A Polio Survivor’s (Baby Boomer) New Year’s Resolution – because Less is often More ! We have to take an active role and know the “why and what” before taking or changing meds. What’s most important is that discussion with our physicians is VITAL.

A Baby Boomer’s New Year Resolution: Ask Your Doctor About Your Medicines

Saint Louis University Geriatrician Says “Less Is Often More”

Released: 26-Dec-2016 5:00 AM EST

Source Newsroom: Saint Louis University Medical Center

Newswise — ST. LOUIS -- If you’re 65 or older and taking more than four medications, resolve to talk to your doctor about doing a New Year’s triage to make sure too many pills aren’t making you sick, advises Milta Little, D.O., associate professor of geriatrics at Saint Louis University.

As people grow older, they can develop a litany of health problems and see multiple specialists who prescribe various drugs to treat common conditions such as osteoporosis, high blood pressure, diabetes, heart disease, arthritis and memory loss.

“Drugs may not play well with each other, and problems can snowball for older adults who take five or more medicines,” Little said.

“As a geriatrician who quarterbackes the health care of my patients, I think six medicines usually is too many, and studies have shown mortality is higher among patients who are taking 10 medicines. I love to analyze medicines my patients are taking because reducing the number of drugs often makes them feel so much better. Many times, less is more.”

Every patient is unique with different health goals and challenges that change as a person ages, which is why one-size-fits-all guidelines don’t work, Little adds. She advocates an annual medicine check-up, where patients ask doctors to assess the drugs they are taking, being mindful that vitamins, supplements and over-the-counter medicines count, too.

“Supplements and other nonprescription medications, which are often less rigorously regulated than prescription medications, are a major cause of dangerous drug-drug interaction in elderly patients,” Little said. “I don’t recommend a multi-vitamin or ginkgo for brain health for everyone. The supplements are for specific people, and I prescribe them like anything else, only for those who need them.”

Here are questions Little asks as she analyzes the medicines her patients take:

How old is my patient? Guidelines on what constitutes good health loosen with age. For instance, a good blood pressure for a younger adult – 120/60 – is much lower than a healthy blood pressure for an older adult – 160/90. And a person who has a blood pressure with a top (systolic) number that’s too low – 130 – could fall or become dizzy, which creates additional health risks. “My prescriptions for patients who are 65 are different than those for patients who are 80,” Little said. “For patients who are 100, I probably wouldn’t prescribe any medicine at all. If they’ve lived to be 100, it’s probably nothing doctors did.”

How long has the patient taken the medicine? Prescriptions are not forever, and should be reviewed periodically to make sure they’re still necessary. “It may have been appropriate for you 10 years ago, but may not be today,” she says. “Under your doctor’s guidance, don’t be afraid to try going off your medicine.” For instance, there is no evidence that shows a 76-year-old patient who has high cholesterol but hasn’t had a heart attack or stroke within the last year would benefit from taking a statin, although he might have been prescribed the statin 16 years ago, when it likely could help.

Is the dosage right? As people grow older their bodies change. A smaller dose of medication might yield the same response as a younger adult. Often times, a half-dose of a psychotropic medication

works better in older patients than a full dose, as does a smaller dose of medicine for osteoporosis. “Start low and go slow,” Little says. “You can always give more but you can’t take it out of the body once it’s given.”

What are the drug’s side effects? A medicine might address one problem, but create another. For instance, antidepressants can cause frequent urination, which can lead to incontinence. Statins and blood thinners worsen frailty, which makes patient vulnerable to more medical problems. An anti-diuretic for blood pressure can worsen symptoms of gout, which is a form of arthritis.

How well do medicines play with each other? Drugs given for one illness could make another condition worse. Medicine given for acid reflux can reduce the effectiveness of blood thinners because of the way the medicines are broken down in the liver.

“Some older adults believe taking a pill will make them healthier, which is not always the case, particularly when they’re taking many pills for different health issues. Too many medicines can make older adults feel fatigued, and undermine the quality of their lives,” said Little, who is the author of an [editorial](#) on overmedication in the elderly that appeared in a 2016 issue of JAMDA.

“We have a lot of evidence that non-medical treatments, such as exercise, yoga and massages, work better in improving a person’s health. But they’re work.”

Established in 1836, Saint Louis University School of Medicine has the distinction of awarding the first medical degree west of the Mississippi River. The school educates physicians and biomedical scientists, conducts medical research, and provides health care on a local, national and international level. Research at the school seeks new cures and treatments in five key areas: infectious disease, liver disease, cancer, heart/lung disease, and aging and brain disorders.

<http://www.newswise.com/articles/a-baby-boomer-s-new-year-resolution-ask-your-doctor-about-your-medicines>

On the topic of Swallowing and Choking issues (12/27/2016)

Original Post: I read *The Polio Paradox* two years ago. Everything that's happening to my body is exactly what you wrote about. Everything is worse, including difficulty swallowing. I have also realized that running out of breath when speaking is pretty frightening.

Dr. Bruno’s Response: Poliovirus-damaged brain stem neurons that control the vagus nerve that carries commands from the brain stem to activate muscles in your throat, esophagus, stomach and intestines, are the cause of swallowing problems. Vagus damage disrupting the normal functioning of the gut may explain our 2000 Post-Polio Survey findings that swallowing difficulty, diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in non-polio survivors.

Polio survivors have also been reporting another problem: Food sticking in the upper esophagus. We think this is due to the vagus not stimulating esophagus muscles to move the food downward. When food gets stuck, irritation triggers a painful esophagus muscle spasm that also stimulates the vagus nerve.

Polio survivors having frequent or severe trouble swallowing problems should see an ENT doctor to find their cause and make sure something other than PPS isn’t causing the trouble. Usually, slowly eating small bites of food, drinking water after each bite, tucking your chin or turning your head to one side when you swallow, swallowing several times, and eating your big meal when you’re most rested is all that’s needed to treat swallowing problems. Talk to your physician. Often, a speech therapist can help you learn tricks to beat your unique problems.

***Editor’s Note:**

There is an informative video about this subject under “Speech Therapy” [HERE](#)

There are now 24 months of “Bruno Bytes” from the Post-Polio Coffee House, in easy to share PDF format, available [HERE](#)

Questions to ask the orthotist (bracemaker)

1. What problem is the brace going to address? Drop foot? A knee that is unstable, or buckles (collapses forward)? A deformity of foot, ankle, knee? a painful joint?
Or a combination of the above?
2. What are the credentials/qualifications of the brace maker?
3. Ask questions and get answers to YOUR satisfaction and level of understanding - examples:
“Explain to me how this brace will address/solve my particular problem(s)”
“Show me what it will look like”
“Can I try an off-the-shelf model or a sample so I can experience what it will be like to wear?”
“If it will be on the leg I use for driving (or other important activity—depress pedals on a piano, etc) how will it impact my ability to do those activities?”
“What choices of a brace do I have?”
“What are the pros and cons of each of these brace designs?”
“What kind of footwear can I wear with this brace?”
“Will I need a different size than I am currently wearing?”
“Can I wear it without shoes?” (personal preference or cultural/religious requirement in certain situations)
4. What about the care of the brace?
Can it be worn in the water?
If there are joints, do they need to be oiled? If so, what kind of oil should I use?
Are there springs/joints/screws that might break or fall out? If so, can I get spare parts to have on hand and be taught how to do my own repairs?
How do I recognize a problem or impending problem with the brace? And what do I do if I suspect a problem?
5. Will gait training be recommended as part of the program? If so, who should do the gait training, what does it entail, etc?
6. How much will the brace cost? How much is my insurance likely to cover? How much will I have to pay out of pocket?
7. Are there any warranties or guarantees?
8. What kind of follow-up is recommended? (Note: most braces DO require some adjustments initially and over time)

Finally, technology is changing and your body may also change, especially if you have post polio syndrome, so it is a good idea to check in with an orthotist at least once every 3-5 years.

Marny Eulberg, MD, is a family medicine physician and a polio survivor. This article, complete with a video interview of Dr. Eulberg available on the PHI website: [HERE](http://www.post-polio.org) (www.post-polio.org)



A Little Humor

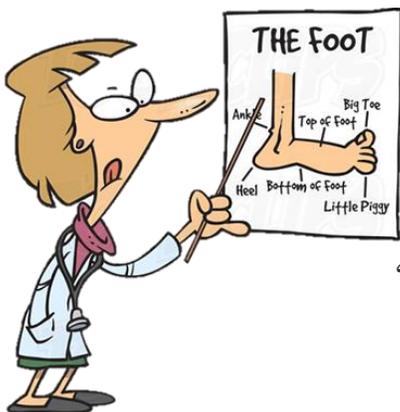
“Learning to be a Doctor”

While making rounds, a doctor pointed out an X-ray to a group of medical students. “As you can see, “ she explained, “the patient limps because his left fibula and tibia are radically arched”.

Turning to her left, she asked one of them, “Michael, what would you do in a case like this?”

“Well,” pondered the student, “I suppose I would limp, too”.

Sent to us from Survivor Ann Silcox. Thanks Ann.



For multiple pages of information about Post-Polio Syndrome:

Check out this section of our website:

<http://www.papolionetwork.org/living-with-post-polio-syndrome1.html>

What IS Post-Polio Syndrome ?

Check out this page on our website. There are definitions from multiple, credible resources as well as the two part video series from our friends in Australia, by Dr. Stephen de Graaf.

<http://www.papolionetwork.org/what-is-post-polio-syndrome.html>

Send us YOUR photo for our slide show of Survivors.

Details available on our website (2nd slideshow on that page):

<http://www.papolionetwork.org/new-stories-of-interest.html>

Would you like to have our Monthly News Updates (8 pages in full color) by US Mail?

Details are available here:

<http://www.papolionetwork.org/contact.html>



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Hold On To
Whatever Keeps you Warm Inside



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Do you have a topic you would like us to cover? Please let us know.

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Know that you are *not* alone.



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